Public health: Community action programme 1999-2003 concerning rare diseases

1997/0146(COD) - 26/05/1997 - Legislative proposal

OBJECTIVE: this proposal seeks to establish a programme on rare diseases for the period from 1 January 1999 to 31 December 2003, with the objective of: - improving information on rare diseases, - supporting patient support groups, - encouraging the creation of response and risk management teams in the event of rare diseases clusters. SUBSTANCE: Definition: rare diseases must be understood as life-threatening or chronically debilitating diseases which are of such low prevalence that specially combined efforts are needed (the generally accepted prevalence of rare diseases is less than 5 per 10 000 of the population - to date there are about 5 000 such diseases in this category). Actions eligible under this programme: 1) information actions on rare diseases to provide information to patients, health professionals and researchers: . creation of a data base on rare diseases, . creation of local, regional, national and Community information networks in order to improve access to information and coordination of existing information systems, . organization of meetings between health professionals in order to improve the identification and prevention of these diseases; 2) actions in support of patient and family support groups in order to establish and strengthen voluntary organizations involved in supporting people affected by these diseases: . aid for the establishment of groups of persons with the same rare conditions or those professionally involved, . establishment of networks of groups and the creation of umbrella bodies encouraging transnational cooperation; 3) actions on handling rare diseases clusters (temporal and physical concentrations or prevalence of rare diseases): . support for the monitoring (sentinel) of rare diseases in order to respond to the demands of detection and treatment of these diseases and the demands of statistical monitoring, . creation of rare diseases response teams and specialised training courses for those investigating clusters, . support for surveillance and early warning systems for clusters, . exchange of expertise in the evaluation and management of clusters of rare diseases that are associated with exogenic causes. Implementation: the Commission will ensure implementation of the programme in close cooperation with the Member States. It will cooperate with the institutions active in this field. In the management of this programme it will be assisted by an advisory committee consisting of representatives of the Member States; Consistency and complementarity: the programme must be implemented in consistency and complementarity with the other relevant Community actions; International cooperation: the programme is open to participation by the associated countries of central Europe and Cyprus and Malta; Monitoring and evaluation: the Commission will ensure the monitoring and continuous evaluation of the programme. It will present an evaluation report to the European Parliament and the Council during the third year of the programme. A final report will also be submitted to Parliament and the Council on completion of this programme; Budget: ECU 1.3 million for the first year (the financial framework for the following four years will be fixed after the establishment of the next financial perspective).